

A National Profile of Family and Unpaid Caregivers Who Assist Older Adults with Health Care Activities

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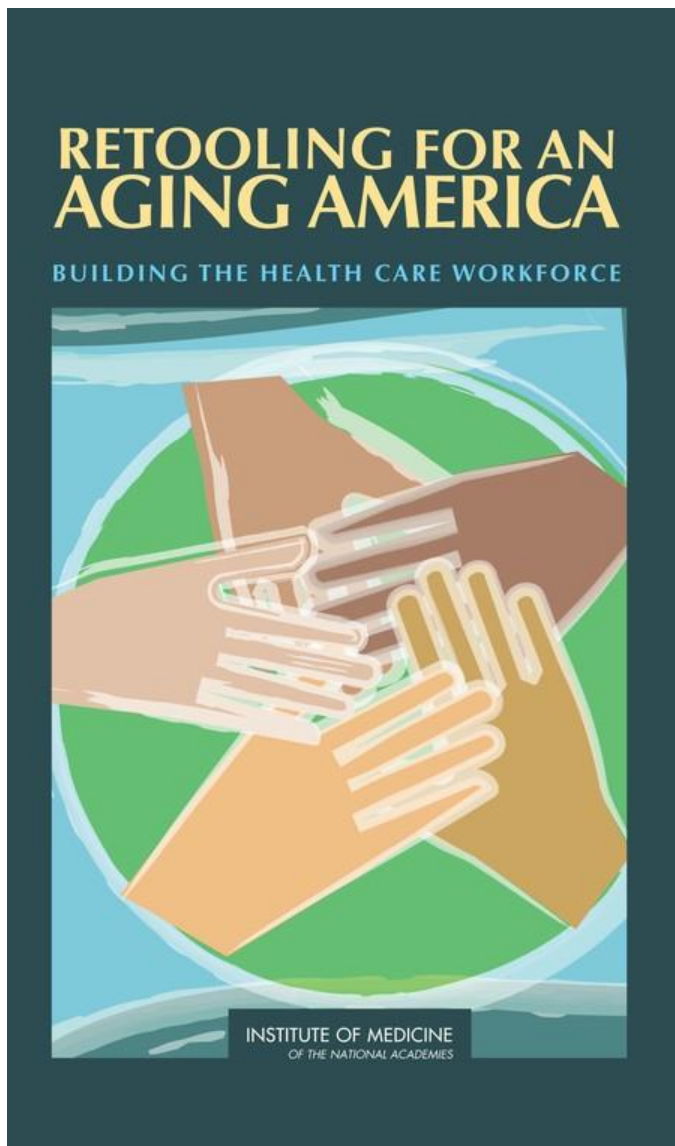
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Health-Related Responsibilities Assumed by Family Caregivers	
Role	Function
Attendant	Provide personal care
Administrator	Manage household
Health Provider	Deliver medical care
Companion	Provide emotional support
Driver	Facilitate transportation
Advocate	Request services
Navigator	Coordinate care across providers and care settings
Coach	Encourage patient self care activities
Technical Interpreter	Facilitate patient understanding
Patient Extender	Facilitate provider understanding

From: Wolff J. Supporting and sustaining the family caregiver workforce for older Americans: Commissioned Paper. 2007:35. Located at: Background Paper for IOM Report: Retooling for an Aging America.

Unpaid. Unappreciated. Untrained.
Undercounted. Exhausted. But vital.

“America’s stealth weapon against chronic illness is a 46-year-old woman with a family, a high-school degree, a full-time job and a household income of \$35,000. She has no particular training in health care. And, to tell you the truth, sometimes she doesn’t feel that great herself...”

-- AMA Medical News, 2001

Background

- About 8 million older adults with disabilities live in the community with help of family and other unpaid caregivers *(Freedman & Spillman 2014)*
- Older adults with disabilities commonly have complex medical needs and are heavy users of health services; coordinating their care is difficult *(IOM, Retooling for an Aging America)*
- Family caregivers not only help with everyday activities, but also help with physician visits, transitional care, and health care tasks such as medication management, injections, and wound care *(Wolff & Roter, 2008 & 2011; Levine et al, 2010; Torke et al, 2014)*
- Family caregivers are not routinely identified or assessed during health care delivery; little is known about the experiences of family caregivers who help manage health care activities or navigate health system demands

Objectives

1. To profile of family and other unpaid caregivers by whether they assist older adults with health care activities
2. To examine how caregivers' involvement in older adults' health care activities relates to caregiving responsibilities and supportive services use
3. To understand how caregivers' involvement in older adults' health care activities relates to caregiving-related effects.

Data Sources

- 2011 National Health and Aging Trends Study (NHATS) and Linked National Study of Caregivers (NSOC)
- Exclusion criteria:
 - Older adult living in nursing home or residential care facility
 - Older adult not receiving self-care (eating, dressing, bathing, toileting), mobility, or household (laundry, bills and banking, shopping, medications) help for health or functioning reasons
 - Older adult exclusively helped by paid non-family caregiver
- Study Sample: Family and unpaid caregivers (n=1,739) assisting older adults living in the community with self-care, mobility, or household activities for health and functioning reasons (n=1,171)
- Represents 14.7 million family and unpaid caregivers assisting 7.7 million older adults

Measures

- Caregivers' socio-demographic & health characteristics: age, gender, educational attainment, co-resident child < 18 years, relationship to older adult, self-rated health (from NSOC)
- Older adults' function: 4-category measure summarizing presence of severe dementia and/or disability (help with 3+ self-care or mobility activities; from NHATS)
- Caregiving circumstances: hours of care (computed per week), travel time to older adults' residence, duration of caregiving (from NSOC)
- Caregiving tasks: 14 specific tasks, categorized by disability-related help, health system logistics, and health management tasks (from NSOC)

Measures: Health Care Activities

Two activities:

- Coordinating care with health professionals – direct interactions (sitting in doctor visits (from NHATS); speaking to or emailing health professionals (from NSOC))
- Managing medications – help keep track of medications or take shots or injections (from NSOC)

Stratified family caregivers by:

- No help: n=364; neither coordinating care or managing medications)
- Some help: n=500; coordinating care OR managing medications)
- Substantial help: n=875; both coordinating care AND managing medications

Measures: Caregiving Effects

Physical, Emotional, Financial Difficulty: Reported level of difficulty due to caregiving, categorized as “Little or none” (0), “Some” (1-2), “Substantial” (3-5)

Participation restrictions: Reduced participation in social/leisure activities identified as “very” or “somewhat” important to the caregiver in the past month (Yes/No)

Work Productivity Loss: (working caregivers (n=656) only)

Summary measure combining:

- Absenteeism: Hours missed due to caregiving in the past month relative to hours typically worked
- Presenteeism: Degree to which caregiving affected productivity while at work (scale of 1-10, expressed as %)

Profile of Family & Unpaid Caregivers

Socio-demographic Characteristics

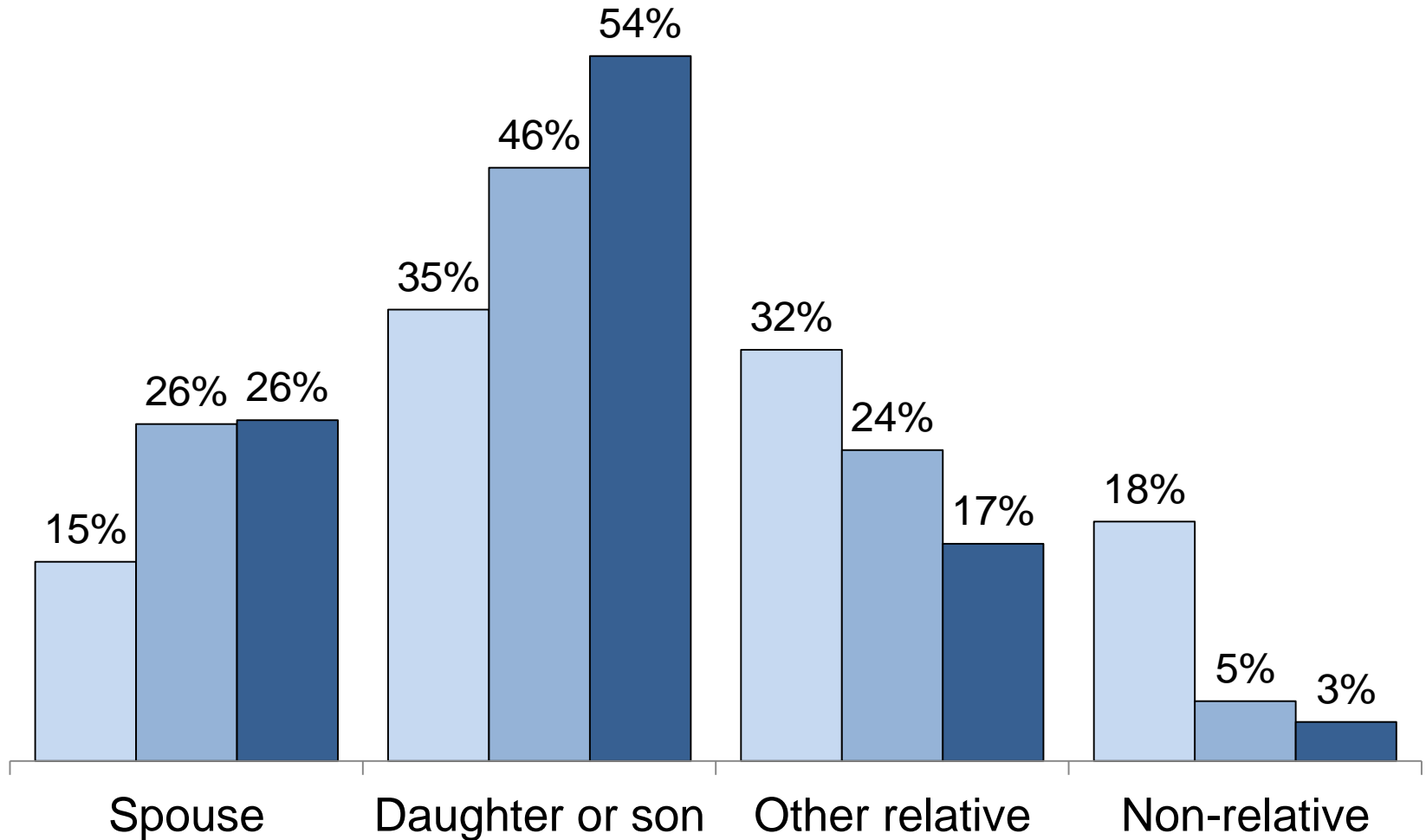
	Substantial Help	Some Help	No Help
Number in millions (% of total)	6.5 (44.1%)	4.4 (29.8%)	3.8 (26.1%)
Age (years)	57.2	55.3	53.4*
Female	69.3%	56.6%**	53.4%**
Educational Attainment			
High School or Less	40.5%	43.3%	48.1%
Some College	35.5%	31.4%	31.0%
College or Beyond	24.0%	25.4%	20.9%
Child < 18 years	18.3%	16.4%	13.8%

*p<0.01; **p<0.001

Family Caregiver Relationship to Older Adult

Caregiver Helps Older Adult with Health Care Activities:

■ No Help (P<0.001) ■ Some Help (P=0.03) ■ Substantial Help (Reference)



Profile of Family & Unpaid Caregivers

Health Status of Caregivers and Older Adults

	Substantial	Some	None
Caregiver Self-Rated Health	(Ref)	P=0.01	P=0.11
- Excellent or very good	44.5%	56.1%	53.5%
- Good	31.1%	24.4%	28.5%
- Fair or poor	24.5%	19.5%	18.0%
Older Adult Function	(Ref)	P<0.001	P<0.001
- No dementia, severe disability	41.5%	63.3%	70.3%
- Dementia only	24.3%	14.3%	13.1%
- Severe disability only	13.1%	12.9%	9.1%
- Dementia & severe disability	21.2%	9.4%	7.5%

Profile of Family & Unpaid Caregivers

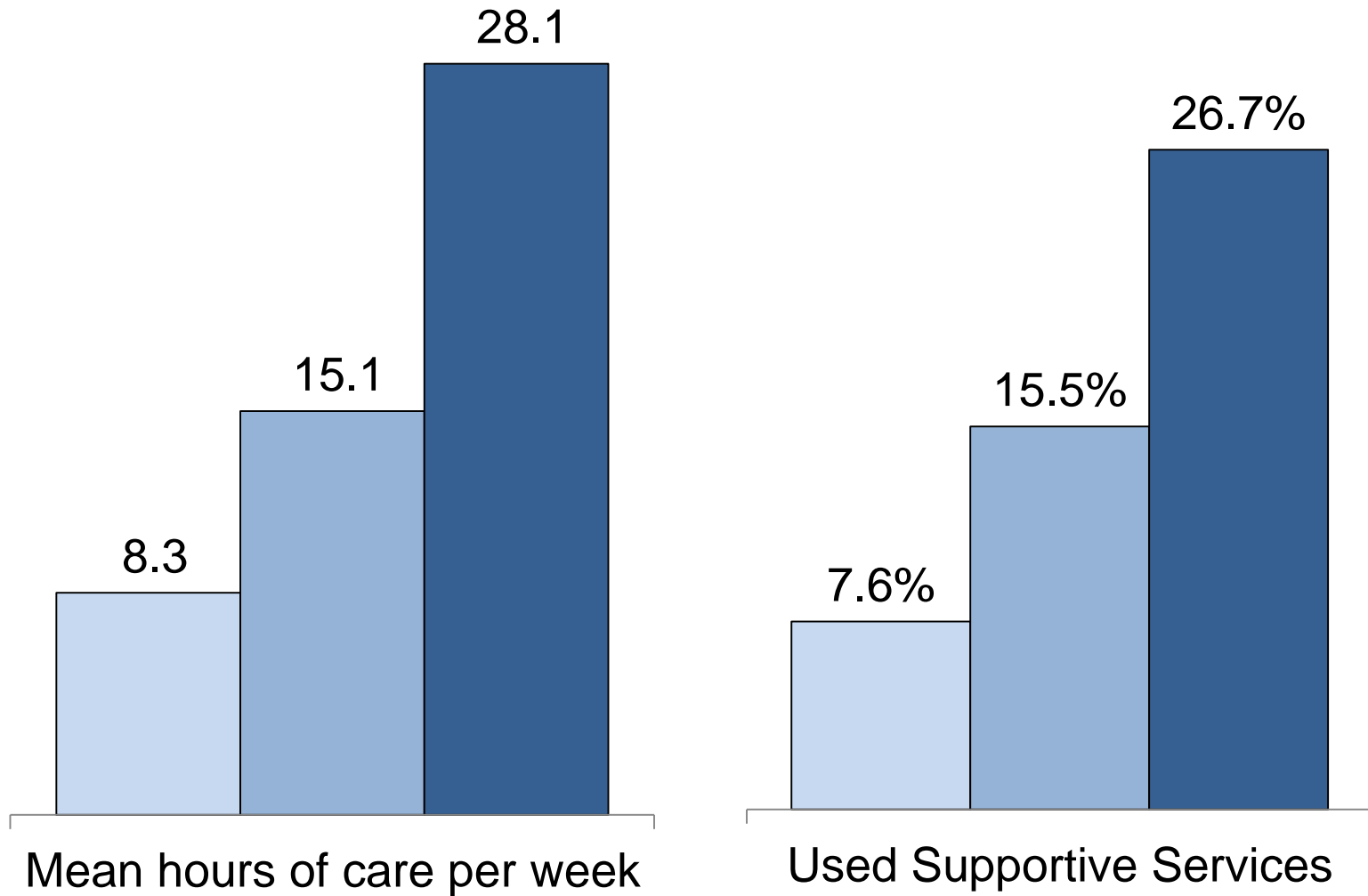
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- Excellent or very good	44.5	56.1	53.5
- Good	31.1	24.4	28.5
- Fair or poor	24.5	19.5	18.0
Older Adult Function	(Ref)	P<0.001	P<0.001
- No dementia, severe disability	41.5%	63.3%	70.3%
- Dementia only	24.3%	14.3%	13.1%
- Severe disability only	13.1%	12.9%	9.1%
- Dementia & severe disability	21.2%	9.4%	7.5%

Intensity of Care Provided by Family Caregivers of Older Adults

Caregiver Helps Older Adult with Health Care Activities:

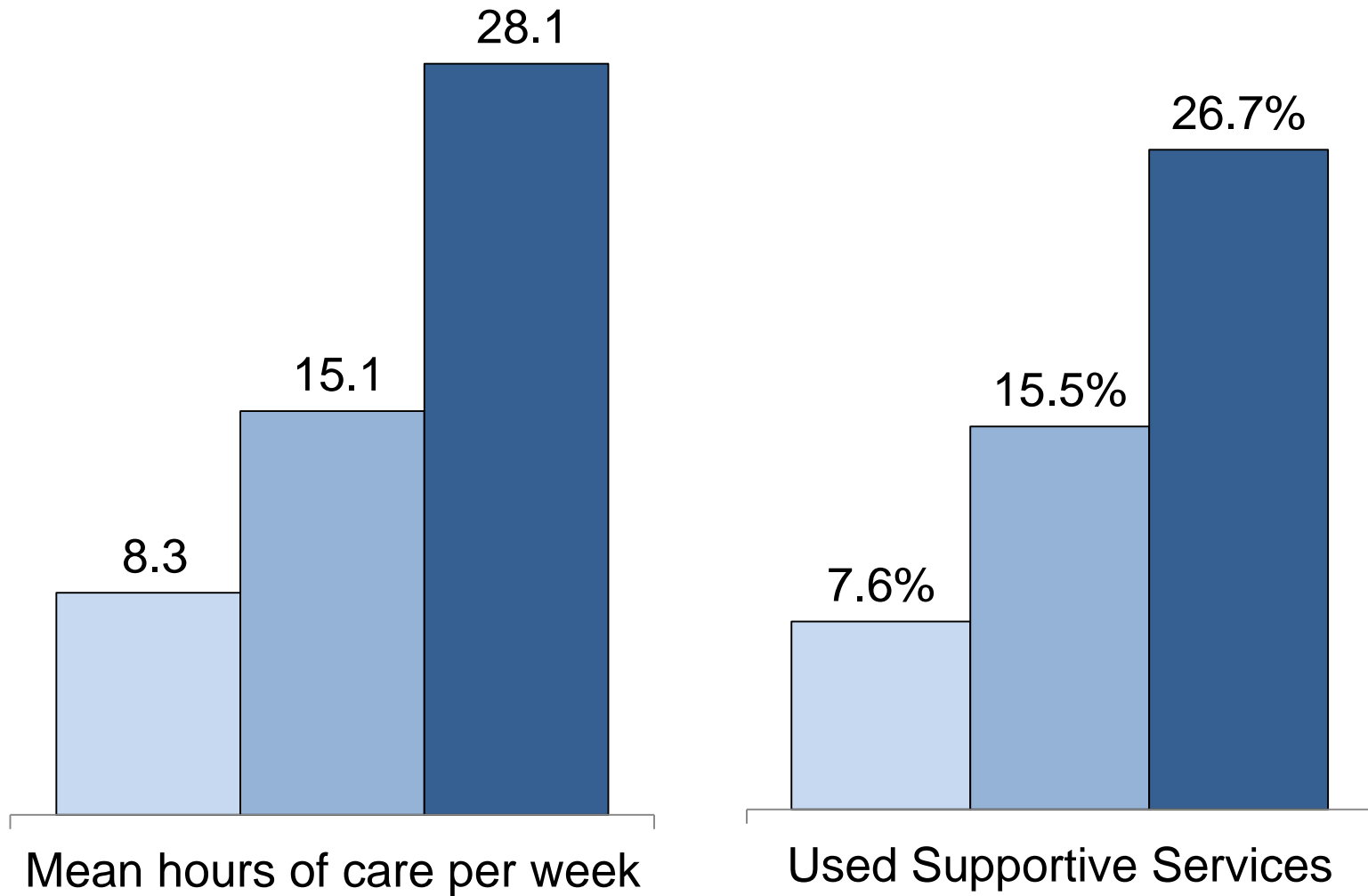
□ No Help (3.8 million) □ Some Help (4.4 million) ■ Substantial Help (6.5 million)



Intensity of Care Provided by Family Caregivers of Older Adults

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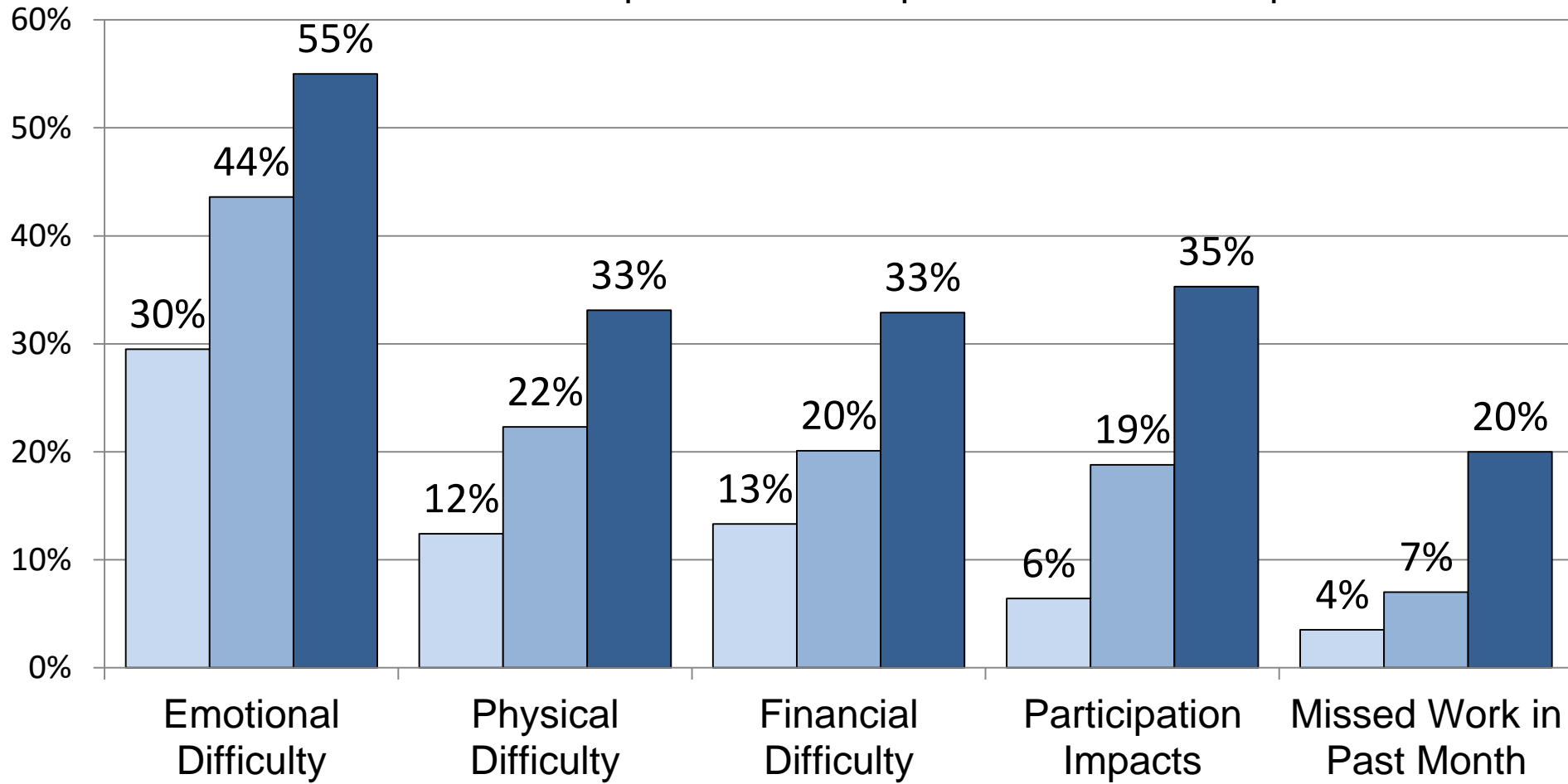
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Caregiving Impacts Among Family Caregivers of Older Adults

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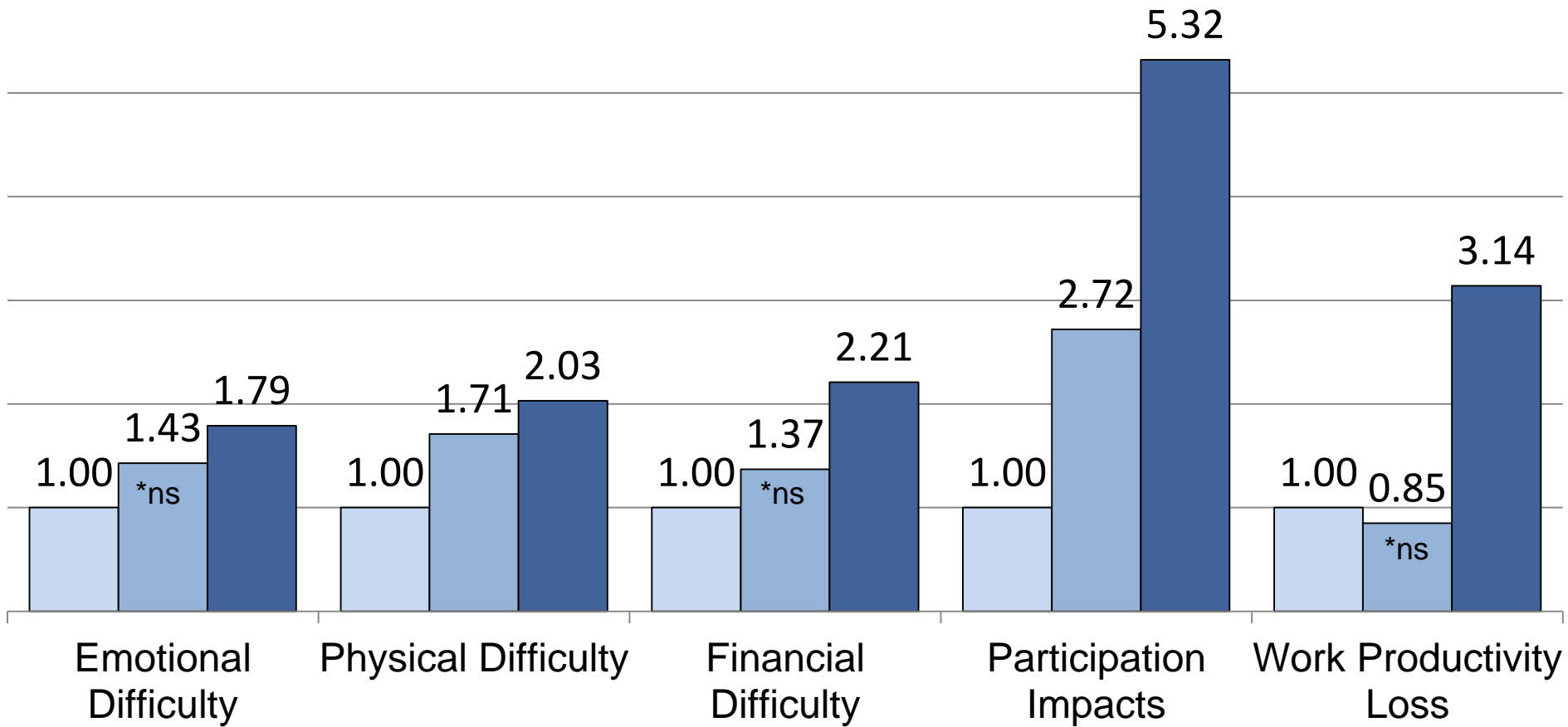
□ No Help □ Some Help ■ Substantial Help



Multivariable Logistic Regression Results: Caregivers' Help with Health Care Activities and Caregiving-Related Effects

Caregiver Helps Older Adult with Health Care Activities:

□ No Help (Reference) □ Some Help ■ Substantial Help



Adjusted for caregiver age, sex, educational attainment, self-rated health, child <18 years in household, work responsibilities, relationship to older adult.

Source: Wolff, Spillman, Freedman, & Kasper, JAMA Internal Medicine 2016.

Conclusions

- Person- and family centered care is not an abstract concept
- Strategies to deliver and measure person- and family-centered care must respect and support individuals' broader social context in which they manage their health.
- The health system is well poised to serve as a point of identification for higher-intensity caregivers who are now largely unrecognized in systems of care
- Efforts to improve quality through team-based care and systems redesign should recognize and better support family caregivers who are already involved and providing considerable amounts of care

Thanks!

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